

23 October 2017

The Principal Research Officer
Joint Select Committee on End of Life Choices
Legislative Assembly of Western Australia
4 Harvest Terrace
WEST PERTH WA 6004

Re Submission

Please find attached our submission for the End of Life Choices of Enquiry of the Western Australian Parliament.

If you have any questions please do not hesitate to contact me.

Yours faithfully

Ms Rhonda Parker Chief Executive Officer



Submission to the End of Life Choices Joint Select Committee of the Western Australian Parliament

The end of life issues the Joint Select Committee has within its scope of consideration are vexed and complex. This submission provides commentary in relation to key end of life issues for people living with dementia.

All individuals should have equity of access to a good birth, good health care throughout the life course and good care to support a death where pain is managed and dignity is supported.

Dementia is now the second leading cause of death in Australia. It creates an added complexity to the palliative process, as it does to other elements of health services delivery, especially in acute settings. Making life choices and decisions regarding future health care while the person is cognitively able to provide informed consent and make their wishes known is important for all, but especially so for those with a diagnosis of dementia.

The mandate of Alzheimer's WA is to support the lived experience of those with dementia and to ensure every individual has access to appropriate, quality health and care services throughout the course of the dementia journey, including the palliative stage. This is far from a reality for the 34,000 Western Australians currently living with a diagnosis of dementia.

The priority of the focus of the end of life debate should first and foremost address the quality and equity of access to palliative care for all across Western Australia, whether in an acute or residential care setting or in the home.

Further, many people do not understand the palliative process, what it is, and what is available. Given the lack of understanding, many do not know what their entitlements are. Many family carers will have proxy consent for treatment of the person with dementia and need to be given the correct information, treatment alternatives and support to empower them to make choices in the best interests of their loved one.

Dementia specialist training and education for primary, community and acute care health system personnel is essential to ensure quality end of life treatment for the person with dementia.

In supporting the end of life, the greatest impact for the greatest number of Western Australians will come from a greater investment in the delivery of palliative care, accompanied by the education of the population about the palliative process.

Alzheimer's WA calls on the enquiry to consider the following as important priorities of end of life care for a person with dementia:

- 1. Equitable access to high quality, evidence based, palliative services in both metropolitan and regional WA
- 2. Expert pain identification and treatment options
- 3. Support for people with dementia to have access to end of life planning and advanced care directives as part of their future planning options
- 4. Grief and loss support for carers and family members
- 5. Information and support to empower families to make informed choices at end of life

Rhonda Parker

CEO

Alzheimer's WA